WOLFRAM SYNDROME UK

Inform, Support, CURE

www.wolframsyndrome.co.uk

Parent's Pack

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This QR code will take you to the Wolfram Syndrome UK website.

This pack has been produced by Wolfram Syndrome UK in support with Birmingham Children's Hospital.

The medical information was produced with guidance by Prof Timothy Barrett Wolfram Syndrome Children's Professional at Birmingham and Dr Renuka Dias Wolfram Syndrome Children's Clinical Lead at Birmingham Children's Hospital.

Family Support Co-Ordinator's (FSC) Details

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This QR code will take you to the Family Support Co-Ordinator's page on the WSUK website or you can use the link - https://wolframsyndrome.co.uk/family-support-coordinator/

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SECTION 3

Clinic Information

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Wolfram Multi-Disciplinary Clinic—Birmingham Children's Hospital

Birmingham Children's Hospital received NCG (National Commissioning Group) funding in 2010 to support multi-disciplinary clinics for patients who have been diagnosed with Wolfram Syndrome.

What does this mean?

We know from talking with those with the syndrome, and those who are undergoing diagnosis, how difficult it is to find doctors at a local level with knowledge of Wolfram, its many different aspects, and the impact that this has on their health care.

Experts have been gathered together from across the fields of Ophthalmology, Neurology, Endocrinology and Genetics amongst others, which has resulted in a major change in how Wolfram is managed, with a focus on Diagnosis, early intervention and good health management.

Which Clinicians will be available?

On the day you may be seen by an:

Ophthalmologist

Orthoptist

Endocrinologist

Neurologist

Geneticist

Clinical Psychologist

In addition, there will be WSUK Family Support Co-Ordinators available to help you with any support needs, who are also available to help at other times.

What happens at an appointment?

You will be invited to spend the day at Birmingham Children's Hospital (BCH) having various tests in the morning followed by lunch, which will be provided by BCH.

During the afternoon you will meet several health professionals in the Rare Disease Centre in Waterfall House.

A play worker, if required, will ensure there are suitable activities on hand for each child.

Consultations with each clinician will last approximately 25 minutes. If any further action is required, each clinician will advise you what will happen next.

What tests may be done?

Your child will have their vision and visual field checked and may have tests such as an ERG (Electro Retina Gram) and/or VEP (Visual Evoked Potential). The Ophthalmology Team may do further tests, and families should be prepared for 2-3 hours in this department.

Your child will also have a blood test and will be asked for a urine sample (you may wish to bring this with you).

If any other tests are required, you will be informed about these on the day.

Please bring any recent local test results or clinic letters with you.

Following your appointment, information and test results will be sent to your local health care team to ensure your child receives optimum care locally. You will also receive a letter outlining your consultation with each clinician.

If you have any questions or concerns about attending the clinic please contact BCH on 0121 333 9267 or the WSUK Family Support Co-Ordinators. (Contact details can be found at the front of the pack).

Example of the children's clinic appointments used by the WS clinic team members

WOLFRAM CLINIC Monday 2nd and Tuesday 3rd October 2023

MRI scans at 9.45, 10.45, 11.45, 13.30, 14.30, 15.30 MUST BE ON TIME

MONDAY 2nd October 2023	Urodynamics Monday **Ward 1 first thing**	ERG - 1 hour	MRI	Orthoptist 08:30am-11:30am	Eye Consultant 13:30pm	Genetics From 13:30pm	Psychology	Neurology pm	Urology
NEW REF L16 DOB: 29.09.2021	N/A	N/A	N/A	N/A	N/A	13:30 To be seen Virtually with Tim	N/A	N/A	N/A
NEW REF **L2** DOB: 07.06.2000		10:30	N/A	08:30	13:30	15:30	11:30	14:00	14:30
F/U L4 DOB: 16.11.2000		N/A	11:45	10:00	15:30	15:00	11:00	14:30	16:00
F/U L3 DOB: 02.01.2000		N/A	09:45	09:00	14:30	14:00	12:30	15:00	13:30
FU L5 DOB: 11.04.2000		N/A	10:45	09:30	14:00	16:00	12:00	13:30	15:30
F/U L6 DOB: 14.08.2000 **Bengali interpreter**		N/A	13:30	10:30	15:00	14:30	09:30	16:00	14:00

Tuesday 3rd October	Bloods	Audiology	Transition	Medical
NEW REF L16 DOB: 29.09.2021	N/A	N/A	N/A	To be seen Virtually on Monday with Denise
NEW REF **L2** DOB: 07.06.2000		N/A	N/A	09:30
F/U L4 DOB: 16.11.2000		10:45	09:30	11:30
F/U L3 DOB: 02.01.2000		11:15	12:00	10:30
F/U L5 DOB: 11.04.2000		11:45	10:30	10:00
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